

Guidebook on

Overcoming System Barriers to Cervical Cancer Screening for HIV-Infected Women in a Clinical Setting

2007 Edition

Providing Healthcare Professionals with Quality Education to Improve HIV Care



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INTRODUCTION

Cervical cancer screening is important for HIV-infected women.

Papanicolaou smears (Pap smears) are screening tests used to detect abnormal cell changes or dysplasia in both the cervix and anus. For women living with HIV, an initial Pap smear should be completed at the time of diagnosis, and then six months later. When the results are normal, this screening test should be completed annually. However, if the results are abnormal, referral to colposcopy, regardless of a woman's degree of immunodeficiency, is commonly recommended by experts. The course of treatment and screening thereafter is dependent upon follow-up test results (*Clinical Manual for Management of the HIV-Infected Adult*, 2006).

Cervical cancer screening for HIV-infected women is critical because there is evidence that prevalence of abnormal Pap smears is more than four times higher in HIV-infected women than in HIV-negative women from the same community (Maiman et al., 1998). Using a case control study design, Maiman and colleagues (1998) found that of the 253 adequate Pap smears completed for HIV-infected women, 32.9 percent were abnormal. Meanwhile, of the 647 adequate Pap smears completed for HIV-negative women, 7.6 percent were abnormal. The sample included women from the New York City metropolitan area from 1990-1993.

Women with cervical dysplasia or early cervical cancer, both of which are associated with human papillomavirus (HPV), are diagnosed through cervical cancer screening, which includes Pap smears and pelvic examinations. HIV-infected women have compromised immune systems and experience common infections such as HPV. HIV-infected women have a higher prevalence of HPV, more persistent forms of HPV, and a

higher incidence of cervical cancer. Invasive cervical cancer is an AIDS-defining illness.

Cultural, social, and system barriers to cervical cancer screening are clearly defined.

While the value of the Pap smear as preventive health tool is clearly defined, the cultural, social, and system barriers that women living with HIV often have to overcome when accessing health care often impede the completion of this screening test and any follow-up tests required for abnormal test results. For example, in 2006, Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) conducted a cross-sectional, multi-site field study to determine how Ryan White CARE Act Title IV programs, now the Ryan White Part D Programs, deliver gynecologic (GYN) services and cervical cancer screening. A particular emphasis of this study was on identifying patient, healthcare provider, and clinical procedural factors that impede or facilitate GYN services and cervical cancer screening. Six sites, from geographically diverse areas, participated in this study which utilized medical record reviews, individual interviews with site coordinators, focus groups with patients and providers, and site/clinic tours as data collection sources. Some of the major themes that arose as facilitators to GYN care from this study included:

- Providers' interest, ability to listen and respect patients, and capacity to perform and explain procedures
- Onsite gynecologic care
- Sufficient space, time, and equipment to provide gynecologic care
- Support staff assistance with follow-up and tracking
- Prompts from providers to perform cervical cancer screening

Furthermore, in a review of 69 Ryan White Programs/CARE Act clinics who were participating in a national quality improvement initiative, Hirschhorn and colleagues (2006) examined differences in care between HIV-infected women and men who utilize services at these clinics. Data sources included 9,015 chart reviews, surveys to clinical directors and up to five providers at each site, and information from Ryan White CARE Act site annual reports. Hirschhorn and colleagues (2006) found that women who seek care at clinics with a high percent of women in the patient population are more likely to have a Pap smear offered or performed, 71 percent versus 58 percent or 60 percent respectively. Furthermore, any gender disparities in care that were observed in this study were related to factors such as patient behavior, provider behavior, or barriers not addressed by caregivers or support services.

When assessing adherence to colposcopy and determining factors associated with non-adherence among a cohort of women in the Women's Interagency HIV Study (WIHS), Cetjin and colleagues (1999) found that adherence to colposcopy recommendations about abnormal cytology was 64 percent in HIV-infected and 73 percent in non-infected women. Colposcopy is one step in the process of screening and diagnosing cervical cancer. Some of the associated factors related to adherence to colposcopy appointments in HIV-infected women were the use of crack or other cocaine within the six months preceding the exam, being too ill to get medical care, and intimate partner violence where entry into or exit from her home was prevented by her partner.

As part of a feminist qualitative study design to explore the experiences of HIV-infected women with abnormal Pap smears and to identify factors affecting why women chose to or chose not to receive follow-up care, Abercrombie (2003) conducted focus groups and individual interviews

with a total of 18 women. Theoretical sampling was used, and only HIV-infected women with abnormal Pap smears were invited to participate. Abercrombie (2003) identified five factors that affected follow-up care for these 18 women:

- 1) Fear of cancer due to family history of reproductive cancers, unfamiliarity with terminology, or history of sexual abuse
- 2) Asymptomatic nature of the problem
- 3) Life circumstances
- 4) Woman's perspectives on health
- 5) Provider qualities

Barriers can be overcome.

Evidence clearly supports the use of cervical cancer screening as a method for identifying abnormal cell changes in ALL women. However, screening is particularly important for women living with HIV because they are more likely to have abnormal Pap smears which are often associated with cervical dysplasia or HPV. Nonetheless, women living with HIV often don't receive cervical cancer screening or other related follow-up GYN care as a result of cultural or social barriers such as substance use or intimate partner violence as well as system barriers such lack of provider training, insufficient equipment, or unsatisfactory tracking, scheduling, or follow-up procedures.

Whether as part of the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) Quality Improvement (QI) initiative or as an initiative driven from within the organization itself, many clinics, community health centers, and other healthcare organizations throughout the United States (US) have begun to tackle the issue of low cervical cancer screening rates for women living with HIV by examining the barriers to care using a plethora of QI tools and through the implementation of strategies to overcome them. This *Guidebook* serves as a compilation of strategies for both identifying barriers and overcoming them.

DEVELOPMENT OF THE *GUIDEBOOK*

Members of the Cervical Cancer Screening Subgroup of the AIDS Education and Training Centers (AETC) Women's Health and Wellness Workgroup developed this *Guidebook* to address system barriers to cervical cancer screening for HIV-infected women. The AETC Women's Health and Wellness Workgroup is a national AETC Workgroup that is coordinated by the AETC National Resource Center (NRC).

Using the *Guidebook*

The barriers to cervical cancer screening experienced by HIV-infected women are well researched and documented. As a result, many clinics, community health centers, and other healthcare organizations have identified mechanisms for identifying barriers in their particular healthcare setting, which in turn led to the identification and implementation of strategies to overcome the barriers. The target audience for the Guidebook includes all clinic staff such as administrators, clinical providers, and support staff. The goals of this guidebook are to:

- 1) Provide instruction on the use of tools such as the fishbone diagram to assess barriers to care
- 2) Illustrate common barriers to care and possible strategies to overcome them
- 3) Present case examples of successful interventions implemented to address low cervical cancer screening rates.

To further assist AETC faculty when providing training on completing fishbone diagrams, an accompanying slide set with speaker notes titled *Using a Fishbone Diagram to Assess Barriers to Cervical Cancer Screening In Your Healthcare Setting* can be adapted to achieve the following learning objectives:

- 1) Describe the rationale for cervical cancer screening and common barriers to completion
- 2) Discuss the benefits of constructing a fishbone diagram to assess causes of a problem
- 3) Identify the steps in constructing a fishbone diagram
- 4) Discuss how the New Jersey HIV Family Centered Care Network successfully used a fishbone diagram to identify and address causes of low cervical cancer screening rates

Related Resources

To address the clinical considerations related to cervical cancer screening, the AETC Women's Health and Wellness Workgroup also developed a Training of Trainers (TOT) package that includes three slide sets, with speaker notes, on:

- 1) Cervical cancer screening with a focus on Pap smears and pelvic examinations,
- 2) HPV
- 3) Sexually transmitted diseases (STDs)

The primary target audience for these slide sets include AETC faculty, who train healthcare providers in primary care or family practice settings. All slide sets can be obtained from the AETC NRC website at www.aidsetc.org. The learning objectives for each slide set can be found below.

Cervical Cancer Screening in HIV-Infected Women: Pap Smears and Pelvic Examinations

- Identify guidelines for cervical cancer screening in HIV-infected women
- Recognize Bethesda system for reporting Pap smear results

- Describe techniques utilized in Pap smear sampling
- Discuss elements involved in pelvic examination
- Analyze the algorithm for follow-up and referral of abnormal Pap smears in HIV-infected women

Human Papillomavirus and HIV-Infected Women

- Define what human papillomavirus (HPV) is and how it is transmitted
- Explain the relationship between HPV, genital warts, and cervical cancer
- Describe the health risks associated with HIV/HPV co-infection
- Discuss screening for HPV and management of women with HIV and HPV
- Describe cultural competency issues related to providing care for women with HPV-HIV coinfection

Common Sexually Transmitted Diseases (STDs) and HIV-Infected Women

- Identify the five most common STDs affecting HIV-infected women
- Discuss clinical presentations associated with the five most common STDs
- Recall methods for diagnosing the five common STDs

Acknowledgements

This tool was developed by the Cervical Cancer Screening Subgroup (Leader: Laura Armas, MD, Texas/Oklahoma AETC) of the AETC Women's Health and Wellness Workgroup (Leader: Laura Armas, MD, Texas/Oklahoma AETC). Authors of the *Guidebook* include:

- Lori DeLorenzo, MSN, RN; Organizational Ideas
- Andrea Norberg, MS, RN; AETC National Resource Center
- Pamela Rothpletz-Puglia, EdD, RD; François-Xavier Bagnoud Center

- Jamie Steiger, MPH; AETC National Resource Center

The *Guidebook* was designed by:

- Karen A. Forgash, BA; AETC National Resource Center

Other collaborating members include:

- Abigail Davis, MS, ANP, WHNP; Mountain Plains AETC
- Rebecca Fry, MSN, APN; François-Xavier Bagnoud Center
- Kathy Hendricks, RN, MSN; François-Xavier Bagnoud Center
- Supriya Modey, MBBS, MPH; AETC National Resource Center
- Peter J. Oates, RN, MSN, ACRN, NP-C; François-Xavier Bagnoud Center
- Jacki Witt, JD, MSN, WHNP; Clinical Training Center for Family Planning

The Workgroup efforts were coordinated by the AETC National Resource Center (Jamie Steiger, MPH and Supriya Modey, MBBS, MPH).

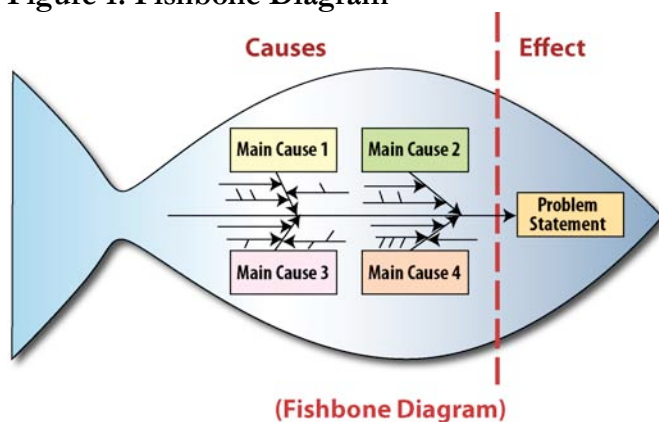
Feedback

The evaluation component of this resource is critical. After reviewing this *Guidebook*, please contact the AETC National Resource Center at info@aidsetc.org with feedback.

ASSESSING THE BARRIERS TO CERVICAL CANCER SCREENING IN YOUR CLINIC

A continuous quality improvement (CQI) tool that can be used to assess the barriers to cervical cancer screening in any clinical setting is a cause and effect diagram. A cause and effect diagram, or a fishbone diagram, is a graphic tool used to identify, explore, and display the causes of a particular problem. It was developed by Kaoru Ishikawa "to represent the relationship between some 'effect' and all the possible 'causes' influencing it" (The Memory Jogger: A Pocket Guide of Tools for Continuous Improvement, 1998). Typically, the effect or problem is listed on the right and the causes of this problem are listed to the left, as presented in Figure 1. "A well-detailed cause and effect diagram will take on the shape of fishbones and hence the alternate name fishbone diagram" (The Memory Jogger: A Pocket Guide of Tools for Continuous Improvement, 1998).

Figure 1. Fishbone Diagram



Benefits of Constructing a Fishbone Diagram

Some of the benefits of constructing a fishbone diagram are (The Balanced Scorecard Institute, 2007):

- Helps determine the root causes of a problem or quality characteristic using a structured approach.
- Encourages group participation and utilizes group knowledge of the process.
- Uses an orderly, easy-to-read format to diagram cause-and-effect relationships.
- Indicates possible causes of variation in a process.
- Increases knowledge of the process by helping everyone to learn more about the factors at work and how they relate.
- Identifies areas where data should be collected for further study.

Steps in Constructing a Fishbone Diagram

The first step in constructing a fishbone diagram is to establish the team who will be involved in the process. A fishbone diagram can be completed by a team including administrators, providers, staff, and consumers. While a fishbone diagram can be completed individually, it is best used in a group or team setting because this allows for a comprehensive review of the problem from multiple perspectives. The facilitator of the fishbone diagram process should have a strong understanding of QI concepts and content knowledge of the issue being explored.

Once the facilitator and team members are identified, the problem being examined must be defined. Using operational definitions is helpful

to ensure that all team members understand the issue being addressed. Once consensus has been reached, the problem statement is placed on the right side of the diagram. Examples of a problem statement are: *Low Pap smear completion rate* or *Pap smear completion rate is 45%*.

The next step is to generate the main causes needed to build the diagram. Typically, there are four causes represented in a fishbone diagram, however the number of main causes can range from three to six. These main causes can be identified through structured brainstorming or by asking team members to track causes as they are completing their daily activities. The main causes of the problem (eg, equipment, systems, patient, provider) are added to the left side of the diagram.

Any additional causes, or related ideas, can be added under the relevant main cause (eg, provider (main cause) uncomfortable completing Pap smears (related idea)). In addition to adding the brainstormed ideas, facilitators of this process can ask the team members "Why does this happen?" and list any related ideas that come from this discussion.

When interpreting the results from the diagram, look at the balance of the diagram and identify which main causes have the most detail. In addition, look at the causes that keep coming up. It is helpful to highlight those causes that can be measured so data can be gathered to determine the frequency of each cause. Finally, circle any causes where immediate action can be taken to remedy to problem.

Case Study: New Jersey HIV Family Centered Care Network

Overview. The New Jersey HIV Family Centered Care Network is a statewide Ryan White Treatment Modernization Act Part D

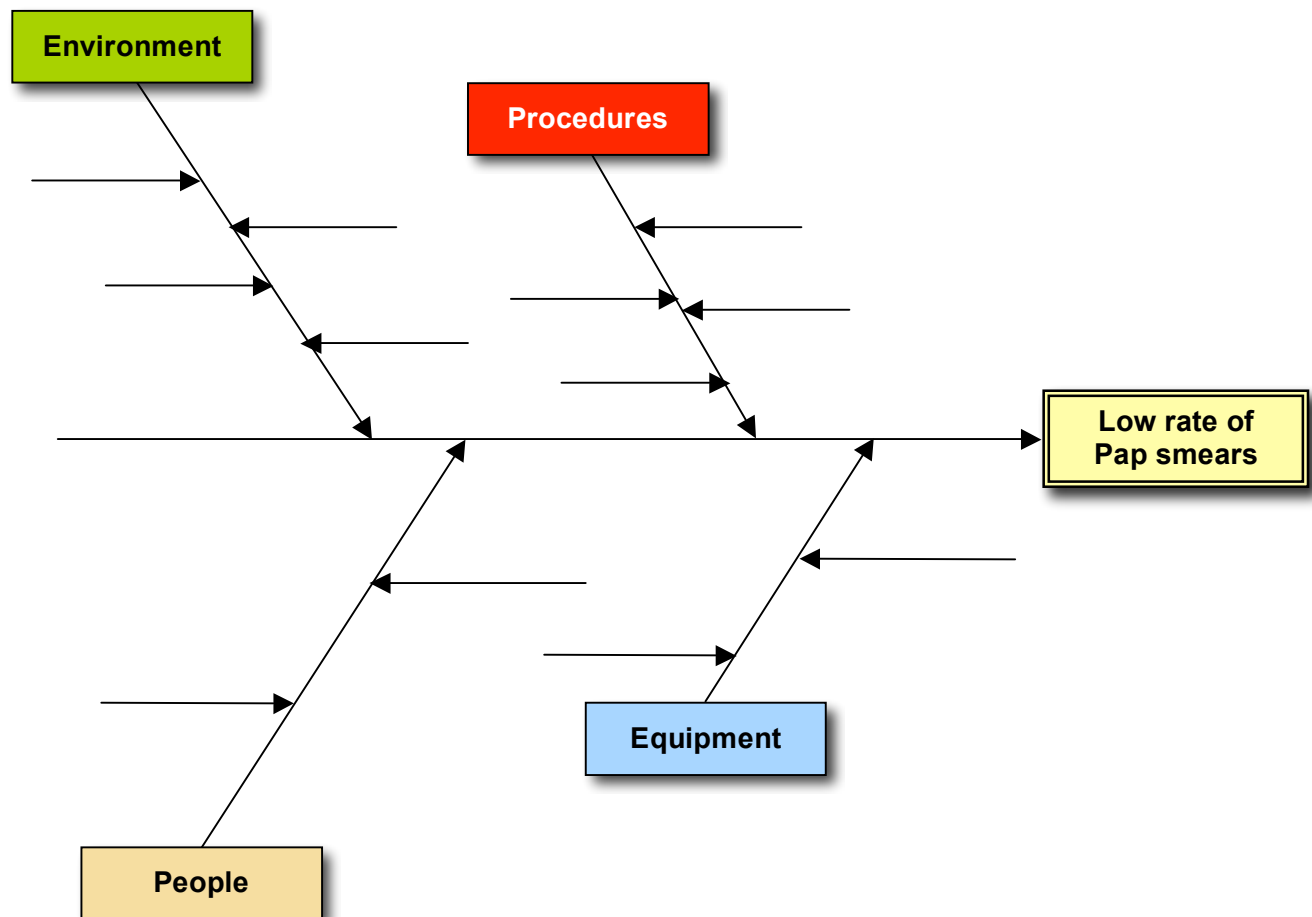
program that is comprised of seven sites and serves the entire State of New Jersey. The sites include university-based clinics, hospitals, medical centers, and satellite sites. A networkwide-CQI process monitors a range of clinical indicators within the Network, such as CD4+ T cell count, viral loads, adherence education, Hepatitis C screening, and cervical cancer screening. As part of the Network's review of data, it was noticed that cervical cancer screening completion rates were variable across all seven sites. Therefore, in an effort to understand the issues and challenges faced by the sites and identify opportunities for change, a root cause analysis was completed using the fishbone diagram.

Process. The root cause analysis process was led by a facilitator who has worked within the Network for 10 years and has extensive experience in QI concepts. The process had representation from each of the Network sites and involved providers, administrators, program coordinators, case managers, and consumers. As part of the process, data from the CQI program were reviewed, past strategies were discussed, and lessons learned were explored. The goal of the root cause analysis was to identify the primary reasons for low completion rates for cervical cancer screening in an effort to identify strategies that could have a lasting, positive impact. Issues were explored using the following four main causes:

- 1) Environment
- 2) Procedures
- 3) People
- 4) Equipment

Figure 2 illustrates how these causes were presented on the fishbone diagram.

Figure 2. New Jersey HIV Family Centered Care Network Root Cause Analysis



The first cause explored was **environment**, which is the physical setting that contributes to low cervical cancer screening completion rates. The four related ideas found by this group were:

- 1) Time available
- 2) Waiting time
- 3) Physical space
- 4) Availability of services

The second cause explored was **procedures**, and included both policies and procedures that did or did not contribute to low completion rates. The four related ideas found by this group were:

- 1) Referral procedures
- 2) Identification of the need for Pap smears
- 3) Patient understanding
- 4) Appointment process

The third cause explored was **people**. This was categorized by staff and patients. Some of the related ideas identified were competing

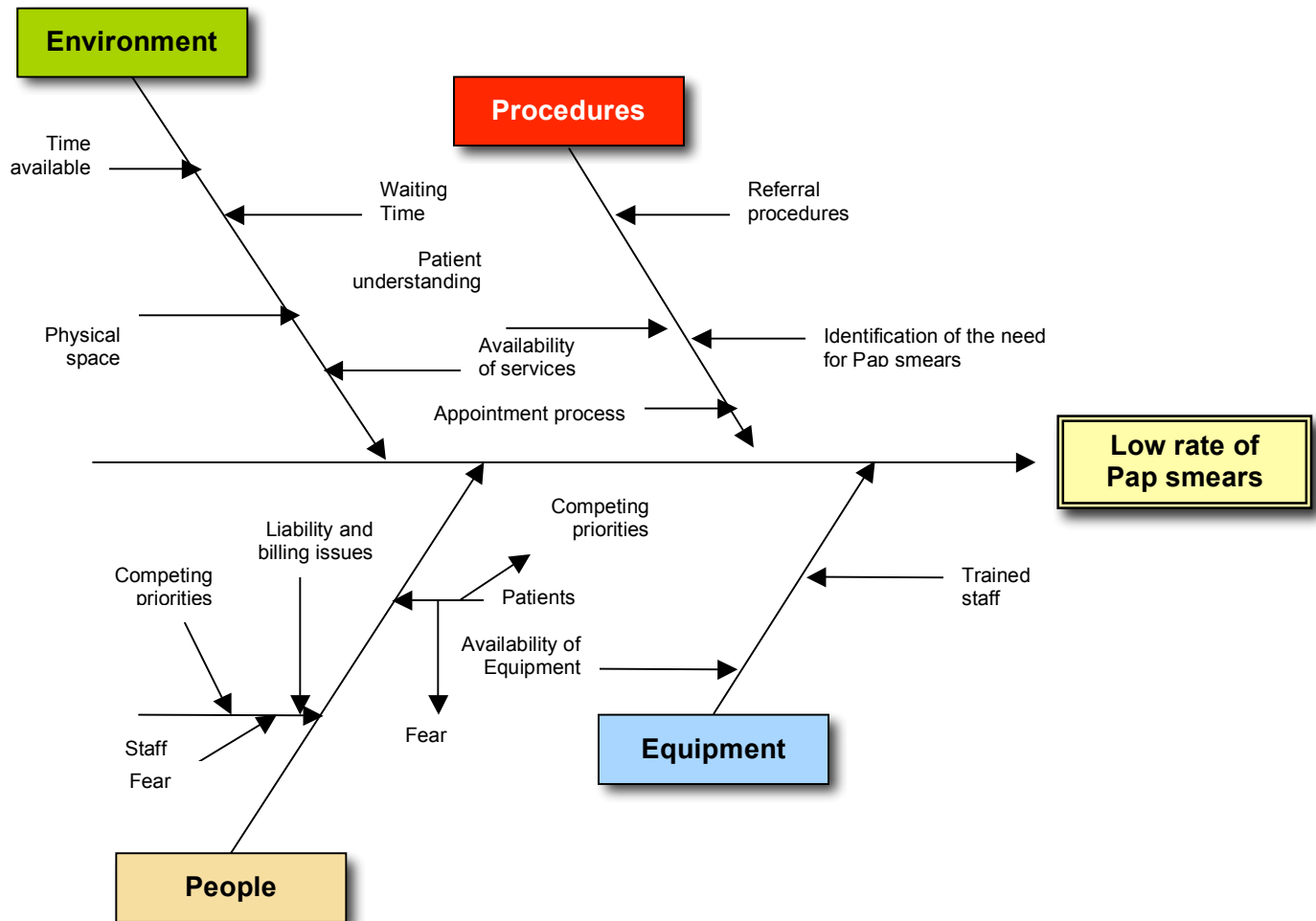
priorities, fear, staff expectations, liability, and billing issues.

The fourth area explored was **equipment**, including what was needed to conduct cervical cancer screening. The two related ideas found by this group were:

- 1) Trained staff
- 2) Physical equipment needed to carry out the procedure

Figure 3 illustrates the completed fishbone diagram, with the related ideas included.

Figure 3. New Jersey HIV Family Centered Care Network Completed Root Cause Analysis



Outcomes. Based on this root cause analysis using the fishbone diagram, the Network conducted a brainstorming session to identify successful and unsuccessful strategies implemented to address the issues identified. The results led to a wide range of potential strategies including the following:

- Build upon the success of referral logs and follow-up with staff to document the outcome of the referral.
- Use incentives to encourage women to complete a Pap smear, such as grocery store coupons.
- Raise staff awareness about low rates of completed Pap smears and strategies that will be employed to address the issue.
- Through the use of existing staff, provide Pap smears onsite instead of referring to an outside source.
- Create a mobile Pap cart that can be wheeled from one exam room to another that holds all of the necessary equipment and supplies.
- Bring a GYN provider onsite to provide the services instead of referring to an outside source.
- Create a prompt on the electronic medical record to notify providers that a Pap smear is due.
- Modify the annual assessment form to include Pap smears and copy the form onto colored paper so that it stands out in the chart.
- Offer “personal” reminders to patients about the need for Pap smears using phone calls and birthday cards.

- Establish formal policies and procedures regarding Pap smears that outline the frequency of Pap smears, referral process, follow-up procedure to document outcome, education of patients, etc.
- Implement a Pap Festival that offers many services of interest to the audience, such as massage therapy, food, or social activities, in addition to the Pap test.

At the end of the discussion about strategies, a Networkwide goal was established. That goal was 70 percent of all women would receive and have documentation of a Pap smear on an annual basis. The goal was established to account for the variability among the sites, with the minimal level of acceptance set at a 70 percent completion rate. For those sites that have rates above 70 percent, there is an expectation that they will maintain or increase their respective rates. Each site was required to implement at least one strategy in an effort to increase the Pap smear completion rate.

Figure 4 describes one of the change strategies that was implemented by the Jersey City Medical Center (JCMC). The information included within the figure outlines a Plan Do Study Act (PDSA) cycle. The problem being addressed was that the Pap smear completion rate was still low after staff education and chart audits. The objective was to entice and introduce women into GYN care via Pap Festivals.

Figure 4. PDSA Cycle Example

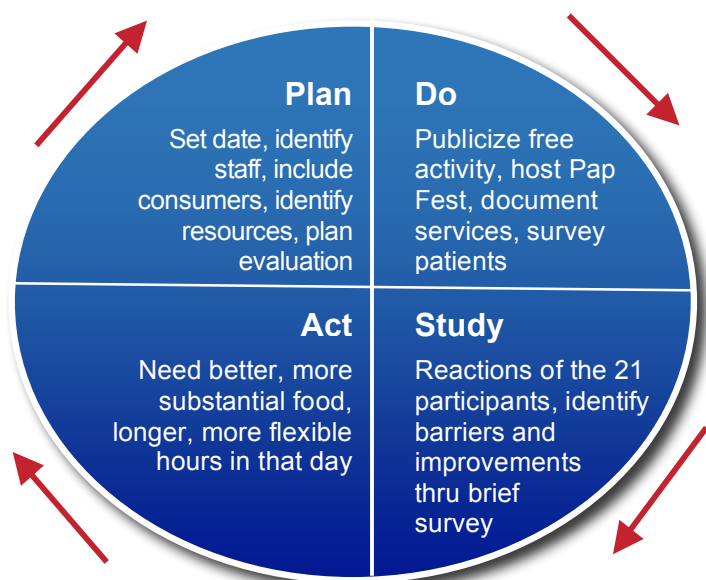
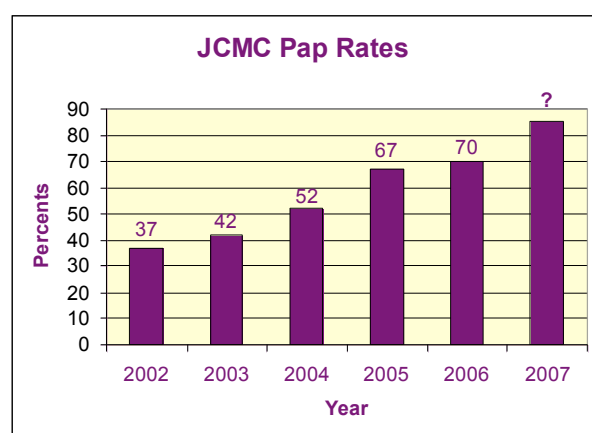


Figure 5 also shows the progress of the JCMC over a period of six years. Each year, different initiatives were tried and the outcome of each initiative is depicted on the bar representing the subsequent year.

Figure 5. Jersey City Medical Center (JCMC) Pap Rates



In 2002, staff education was the focus of the intervention. This, however, was limited to telling the providers at the seven network sites to

conduct Pap smears, thinking they would naturally get done. As presented in the data, these efforts alone made very little difference. In 2003, chart audits were completed. By focusing on the data and documentation, this task alone raised the screening rates about 10 percent. In 2004, Pap Festivals were held and a small incentive program was initiated. Women who were reluctant or unwilling to get a Pap smear were told that if they accepted a referral and got a Pap smear, when the results reached the HIV clinic, they would receive an incentive such as a grocery store coupon. This raised the rate to 52 percent. Also in 2004, and in 2005, cervical cancer screening was brought into the HIV clinic. One Adult Nurse Practitioner (ANP) began to conduct Pap smears when a woman came in for an HIV visit. It became much easier for the ANP when in 2006, an RN was added who does a lot of up front work for the ANP. She identifies which women are coming in for an HIV visit, and which need a Pap smear completed. She can make sure that the woman is seen in the appropriate room and that the ANP has the time and tools she needs to get the job done. The most recent 2007 intervention brought an OB/GYN nurse practitioner into the clinic. By having this provider readily available, visible, familiar, and accessible to the patients, who knows where the results will take them!

Lessons Learned and Best Practices. The process of utilizing the fishbone diagram to examine cervical cancer screening shed light on lessons learned at two levels: **1)** utility of the QI tool and **2)** specific strategies for addressing the issue.

In respect to the use of the fishbone diagram itself, it is important to utilize a skilled facilitator who clearly understands the purpose of the fishbone diagram and has the ability to structure or redirect discussion, as needed. Without having someone knowledgeable about the QI tool, the discussion could have easily been derailed,

leaving participants feeling frustrated. It was also important to consider the number of people participating in the process. Too many people and the lack of a skilled facilitator could turn the process into chaos.

The New Jersey HIV Family Centered Care Network felt the process itself was energizing and a new found sense of enthusiasm among providers to tackle the issue was identified. It was also acknowledged that input from different perspectives was most productive, including input from consumers. By having broad representation, barriers that weren't previously identified were highlighted and new strategies could be put forth.

In respect to identifying barriers and specific strategies to employ, the process facilitated sharing of information, including strategies that

worked and did not work. By having all seven sites at the table discussing the issue, new solutions were identified that hadn't previously been tested. For instance, one site hosted Pap Festivals, which resulted in significant patient participation. None of the other sites were aware this was being conducted. Since that time, three other sites have hosted similar events.

It is also important to discuss strategies that were not effective. While strategy #1 didn't necessarily work for site A, sharing the information with the other six sites allowed the strategy to be tested in other settings. It was also helpful to acknowledge barriers can be unique to a particular site.

By the end of the process, the New Jersey HIV Family Centered Care Network staff became "internal consultants" for each other—what stronger statement can be made?

COMMON SYSTEM BARRIERS AND STRATEGIES TO OVERCOME THEM

Below is a table with common system barriers to cervical cancer screening and strategies to overcome them. The list of strategies within each barrier may have some conflicting ideas. All possible strategies were included because it is important to find the remedy that best fits the needs of the clinical setting and patient

population. This may vary by site. These strategies are recommendations that have been made by members of the AETC Women's Health and Wellness Workgroup based on their clinical experiences or based on discussions within the Workgroup, and therefore may not have been evaluated.

Common Barrier	Strategy
Consumer access to information	<ul style="list-style-type: none"> Create a resource list of patient education materials (<i>see Appendix A to view a sample</i>) Offer patient education materials in different locations throughout the clinic setting Offer information using a variety of mechanisms such as brochures, newsletters, or community-based forums (<i>see Appendix B to view samples</i>)
Accessibility	<ul style="list-style-type: none"> Integrate GYN care and cervical cancer screening into regular clinic visits for one stop care Offer Pap Festivals Set up Pap smear only appointments Create walk-in hours for Pap smears Increase number of providers qualified and trained to conduct Pap smears onsite Title X family planning clinics may be a resource for providing Pap smears onsite
Missed appointments	<ul style="list-style-type: none"> Implement an intensive tracking system Make reminder calls to the patient Have bilingual staff available to assist in scheduling appointments Schedule appointments for cervical cancer screening when the patient is also at the clinic for primary care Utilize outreach and case management teams Train all front desk staff on the importance of cervical cancer screening
Lack of trained and culturally competent providers	<ul style="list-style-type: none"> Train providers on how to do a Pap smear Train providers on issues that may impact a woman's decision to complete cervical cancer screening (ie. Intimate partner violence) Train providers on how to use equipment such as a colposcope Train providers on how to assess the health literacy level of their patients Train providers to listen to patients Providers should approach patients in a non-judgmental, compassionate, and sensitive manner

Documentation	<ul style="list-style-type: none"> ■ Create and implement tracking and patient information forms (<i>see Appendix C for samples</i>) ■ If using electronic medical records, establish a system where Pap smear results are easy to obtain ■ Utilize MS Access to create a locked database that tracks appointment status, completion of Pap smears, and reasons for not completing a Pap smear
Equipment	<ul style="list-style-type: none"> ■ Create a mobile Pap cart that has all of the necessary supplies and can be wheeled from one exam room to another ■ Utilize a checklist for material needed to conduct a Pap smear to ensure that materials and equipment are collected and available ■ Place a picture of a completely equipped room and prep tray in the exam room to serve as a visual cue for ensuring all materials are available ■ Equip all rooms with stirrups
Childcare	<ul style="list-style-type: none"> ■ Offer childcare services onsite ■ Create a child-friendly play space in the clinic setting ■ Utilize volunteers or interns to assist with childcare
Transportation	<ul style="list-style-type: none"> ■ Provide public transportation vouchers ■ Utilize transportation services available at your healthcare setting ■ Coordinate appointments to minimize number of trips required
Exam rooms	<ul style="list-style-type: none"> ■ Provide a space that is large enough to accommodate women with children, including a privacy curtain ■ Equip all rooms with stirrups
Fear factor (Provider)	<ul style="list-style-type: none"> ■ Provide training on topics relevant to cervical cancer screening and providing quality care to women living with HIV ■ Utilize models so providers can gain experience completing an exam
Fear factor (Consumer)	<ul style="list-style-type: none"> ■ Provide patient education materials that address cervical cancer screening terminology and information about female reproductive anatomy (<i>see Appendix B to view samples</i>) ■ Begin educating girls and women early about the benefits of GYN care and Pap smears. ■ Providers should engage in trust building exercises with their patients (eg., provider should describe what will occur at the appointment and provide information about when a patient should return for follow-up care) ■ Providers should be aware of their patients' possible family history of reproductive cancer ■ Nurses and support staff can prepare the patient by reminding them that they are scheduled for a Pap smear, particularly if it is during a regular exam
Referral Process	<ul style="list-style-type: none"> ■ Offer all services in one location ■ Assign each patient to a staff member or provider who will monitor the referral process ■ Create a calendar for patients with a schedule of all medical appointments ■ Build a relationship with the program you are referring a patient to by identifying one or two contact people in that program so you can give your patient their name specifically ■ Title X family planning clinics are one referral resource for screening

CASE STUDIES

This section of the *Guidebook* contains two case studies that showcase successful strategies for addressing system barriers. The strategies are organized by people, environment, procedures, and equipment. Information for these case studies was obtained from a multi-site field study of GYN care and cervical cancer screening, which was carried out by the François-Xavier Bagnoud Center and funded by HRSA HAB in 2005-2006.

Case Study 1:

People: Seven hundred patients access this HIV medical care center; 50 percent of the patient population are women. This site has an experienced nurse practitioner dedicated to providing GYN care and cervical cancer screening. Women come in for their regular HIV medical care and are seen for GYN care at the same visit. The nurse practitioner connects with patients and provides “tough love,” as relayed by the patients. These women maintain that the nurse practitioner has a unique ability to promote self-management.

Environment: The space in the clinic is minimal, but there is a room dedicated for the nurse practitioner. This room is small, yet is large enough for children to be behind a curtain if they accompany their mother to the visit. The room is equipped for providing GYN care.

Procedures: The nurse practitioner keeps a log of her patients’ Pap smear dates, results, follow-up appointments, etc. and also communicates with other departments when women are referred for colposcopy. A system is set up to provide the infectious disease team with electronic prompts to remind them when a patient needs a Pap smear or follow-up colposcopy. Additionally, a nurse routinely checks the medical records for

Pap smear dates and will remind both patients and providers about these dates. The nurse, who is bilingual (English/Spanish), will typically deliver reminders to the patients through telephone calls or through the mail. Overall, this system has multiple procedures for reminding providers and patients about cervical cancer screening and follow-up. It was relayed by patients and providers that the prompts and follow-up procedures increase cervical cancer screening rates at this site.

Equipment: Colposcopy is performed off site, but the GYN exam room is fully equipped for comfortable GYN care and cervical cancer screening.

Case Study 2:

People: Three hundred patients come to this HIV care center for care and treatment; 10 percent of the patient population include women. Ninety five percent of the women receive case management services, and all women entering care are followed closely by their case manager for their first six months in care. This site has a case manager dedicated to educating and reminding women about cervical cancer screening and the importance of GYN care. Patients maintain that the case manager is the reason they return for regular GYN care and screening. The case manager also utilizes peer educators who speak with women during clinic hours and group meetings.

Environment: GYN care is provided during regular medical care visits. All medical staff, including medical residents, are trained in performing cervical cancer screening and colposcopy is performed onsite. Support staff are available to watch children for mothers during their GYN

Procedures. Women relayed that the center supports them in self-advocacy, and women described feeling empowered by making research and health care decisions. This site has information about research and treatment everywhere, including the women's bathroom. In addition, there are many support groups for women, including groups specifically to support recent immigrants.

Procedures: The nurse case manager tracks the patients' Pap smear dates and provides reminder phone calls, letters, and community outreach. The nurse case manager also checks the patients'

chart prior to each visit and completes the HIVQUAL flow sheet with cervical cancer screening indicators. This flow sheet is placed on the top of the medical record with a paper clip, to remind providers of the Pap smear dates, etc. Nursing personnel also verbally remind the providers to performing Pap smears, and they also prepare the patient by reminding them that they need a Pap smear during the visit.

Equipment: The clinic has seven exam rooms, all of which are equipped for GYN care. One room also has a colposcope. One provider is trained to perform colposcopy.

CONCLUSION

Cervical cancer screening is important for all women, however it is critical for HIV-infected women as they are more than four times likely to have an abnormal Pap smear than HIV negative women (Maiman et al., 1998).

Furthermore, HIV-infected women have a higher prevalence of HPV and a higher incidence of cervical cancer. Invasive cervical cancer is an AIDS-defining illness.

Screening for cervical cancer through Pap smears can have a significant impact on morbidity and mortality. Nonetheless, it is evident that there are many cultural, social,

and system barriers that impede the completion of cervical cancer screening for HIV-infected women. A fishbone diagram is one CQI tool that can be used to examine a problem such as low cervical cancer screening rates. The process of completing a fishbone diagram is used not only to identify the causes of a problem, but to encourage discussion of strategies for remedying the issues at hand. As highlighted in this *Guidebook*, there are many strategies that can be implemented to address the range of system barriers that may impede cervical cancer screening in your clinical setting.

REFERENCES

- Abercrombie, P.D. (2003). Factors Affecting Abnormal Pap Smear Follow-Up Among HIV-Infected Women. *Journal of the Association of Nurses in AIDS Care*, 14(3), 41-54.
- Anderson, J.R, ed. (2001). *A Guide to the Clinical Care of Women with HIV*. Health Resources and Services Administration HIV/AIDS Bureau.
- Brassard, M., ed. (1998). *The MEMORY JOGGER: A Pocket Guide of Tools for Continuous Improvement*. Methuen, MA: GOAL/QPC.
- Cervical Dysplasia. In: Coffey S, ed. *Clinical Manual for Management of the HIV-Infected Adult*, 2006 Edition. AIDS Education & Training Centers National Resource Center; 2006:(6) 13-15.
- Cetjin, H.E. et al. (1999). Adherence to Colposcopy Among Women With HIV Infection. *Journal of Acquired Immune Deficiency Syndrome*, 22(3), 247-56.
- Health Resources and Services HIV/AIDS Bureau. (2006). *Gynecologic Care and Pap Screening in Ryan White CARE Act Title IV Programs: Summary of Results* (U69 HA 0049-03-00). Rockville, MD: HIV/AIDS Bureau.
- Hirschhorn, L.R. et al. (2006). Gender Differences in Quality of HIV Care in Ryan White CARE Act-Funded Clinics. *Women's Health Issues*, 16, 104-112.
- Maiman, M. et al. (1998). Prevalence, Risk Factors, and Accuracy of Cytologic Screening for Cervical Intraepithelial Neoplasia in Women with the Human Immunodeficiency Virus. *Gynecologic Oncology*, 68, 233-39.
- New York State Department of Health AIDS Institute. (2000). Promoting GYN CARE for HIV-Infected Women: Best Practices from New York State. Retrieved on July 12, 2007 from <http://www.ihl.org/IHI/Topics/HIVAIDS/HIVDiseaseGeneral/Tools/PromotingGynecologicalGYNCareforHIVInfectedWomen.htm>
- Shuter, J., Kalkut, G.E., Pinon, M.W., Bellin, E.Y., & Zingman, B.S. (2003). A computerized reminder system improves compliance with Papanicolaou smear recommendations in an HIV care clinic. *International Journal of STD & AIDS*, 14(10), 67-80.
- The Balanced Scorecard Institute. Basic Tools for Process Improvement Module 5: The Cause and Effect Diagram. Retrieved on July 12, 2007 from www.balancedscorecard.org/files/c-eddiag.pdf

APPENDIX A: SAMPLE LIST OF PATIENT EDUCATION MATERIALS

Source: New York State Department of Health AIDS Institute. (2000). *Promoting GYN CARE for HIV-Infected Women: Best Practices from New York State*. Available for download at <http://www.ihl.org>

APPENDIX A CLIENT EDUCATION MATERIALS

Many publications, educational videos and on-line resources, including those listed here, exist for patient education. Prices of publications and videos are subject to change.

Publications

Abnormal Pap?

American Social Health Association.

This patient-friendly brochure explains what an abnormal Pap result means and gives possible causes. It also explains HPV and the importance of regular Pap smears for women of all ages. Colposcopy, biopsy and the difference between a Pap smear and pelvic exam are defined. Tips for preparing a Pap smear and space to write in the next appointment and questions for the doctor are included. Price: up to 499: 26 cents each; 500-999: 24 cents each; 1000 or more: 22 cents each. To order call 1-800-783-9877 between 8 am — 4 pm (EST).

GYN Exams Can Save Your Life!

Planned Parenthood Federation of America.

This pamphlet stresses the critical, lifesaving importance of routine gynecological care. Written and designed to be read quickly and easily, it contains no complex, lengthy explanations, just the hard and fast reasons why every woman must have regular GYN check-ups. Price: \$3.00 each; or 100 -- \$10.00; 500 -- \$40.00; 1000 -- \$60.00. To order call (212) 261-4656 or visit PPFA's website at the address given on page 33.

Hagase la pruedba Pap: Hagalo Hoy...Por su salud y su familia!

(Have a Pap Test...For Your Health and Your Family!) National Cancer Institute, NIH

This bilingual brochure tells why it is important to get a Pap test and gives concise information about where to get a Pap test and how often the Pap test should be done. (Available also in an English version, Pap Test: A Healthy Habit for Life!) Price: Free -- (No shipping and handling charge for orders of 20 or fewer items). To order call 1-800-422-6237 or visit NCI's website at the address given on page 33.

Having a Pelvic Exam and Pap Test,

National Cancer Institute, NIH

This easy-to-read brochure uses pictures to describe what a woman will experience when getting a Pap test and a pelvic exam from a health care provider. Price: Free -- (No shipping and handling for orders of 20 or fewer items). To order call 1-800-422-6237 or visit NCI's website at the address given on page 33.

The Pap Test,

American College of Obstetricians and Gynecologists.

This pamphlet tells who should have a Pap test, how often the test should be done, and what the results mean. Price: \$17.50 for a pack of 50. To order call 1-800-762-2264.

Pap Tests: A Healthy Habit for Life!

National Cancer Institute, NIH

This easy-to-read color brochure tells women about the importance of getting a Pap test. It explains who should get a Pap test, how often it should be done, and where to get the test. Price: Free -- (No shipping and handling charge for orders of 20 or fewer items). To order call 1-800-422-6237 or visit NCI's website at the address given on page 33.

La Prueba Pap: Un m todo para diagnosticar el c ncer del cuello del tero,

National Cancer Institute, NIH

This 16-page booklet in Spanish answers questions about the Pap test, including how often it should be done and the significance of test results. It also describes other diagnostic tests and treatments. Price: Free -- (No shipping and handling charge for orders of 20 or fewer items). To order call 1-800-422-6237 or visit NCI's website at the address given on page 33.

Some Questions and Answers About HPV and Genital Warts,

American Social Health Association.

This pamphlet, available in English and in Spanish versions, explains the viral infection that sometimes causes warts and answers the most frequently asked questions about HPV. It also addresses the evidence linking HPV with cervical cancer and stresses the importance of the Pap smear. Price: up to 499 items -- 30 cents each; 500-999 items -- 28 cents each; 1000 or more items -- 26 cents each. To order call 1-800-783-9877 between 8 am — 4 pm (EST).

Taking the Mystery Out of GYN Exams,

Presbyterian Hospital HIV Clinical Education Initiative, Columbia-Presbyterian Medical Center, New York, NY.

This eight-panel educational brochure, available in English or Spanish, provides a detailed description of what to expect before and during a GYN examination. In clear, straightforward language, the brochure explains the reasons why GYN care is so important as well as other ways that women can protect their health, such as safer sex, healthy diet, stress management, and routine health care. Price: Free -- To New York State providers. To order call (212) 305-2985.

What You Need to Know About Cancer of the Cervix,

National Cancer Institute, NIH

This pamphlet discusses symptoms, diagnosis, treatment, emotional issues, and questions to ask the doctor. It also includes a glossary of terms and other resources. Price: Free -- (No shipping and handling charge for orders of 20 or fewer items). To order call 1-800-422-6237 or visit NCI's website at the address given on page 33.

Your Key to Good Health: The Gynecological Exam,

Planned Parenthood Federation of America.

Regular gynecological check-ups are critical to women's good health and preventing serious, life-threatening illnesses. This pamphlet dispels all mysteries with a thorough explanation of everything that happens in an exam and why. It also covers how often women should have an exam and how they should prepare for it. Price: \$3.00 each; 100 -- \$30.00; 500 -- \$125.00; 1000 -- \$200.00. To order call (212) 261-4656 or visit PPFA's website at the address given on page 33.

APPENDIX B: SELECTED PATIENT EDUCATION MATERIALS

Source: U.S. Department of Health and Human Services, Public Health Service, Office of Population Affairs.

For information contact:

This brochure was produced with a grant from the Office of Population Affairs, 2005.

U.S. Department of Health and Human Services
Public Health Service
Office of Population Affairs

Printed on recycled paper.

Bring this card with you when you have a Pap smear.
This card can be folded and put in your wallet.

What is a Pap smear?

- A test which may be done as a part of a pelvic exam
- A test to prevent cancer of the cervix—the opening of the uterus. It can find abnormal cells of the cervix before they become cancer
- The health care provider takes cells from the cervix through the vagina during a pelvic exam
- The Pap smear is not a test for pregnancy or for sexually transmitted diseases like gonorrhea or Chlamydia or AIDS

When is the best time for a Pap smear?

- One to two weeks after your period is over
- After any bleeding or infection in the vagina has been treated or is cleared up

How often should I get a Pap smear?

- Once a year if 18 or older
- Once a year if you ever had sex (penis in the vagina)
- More often if your Pap smear is abnormal

How do I get ready for a Pap smear?

- Do not have sex (sexual intercourse, penis in the vagina) for 2 days before the test
- Do not wash the vagina or douche for 2 days before the test
- Do not put anything in the vagina for 2 days before the test. No tampons, sponges, douches, cervical caps, diaphragms, creams, foam, condoms or penis.

How will I know if I have an abnormal Pap smear?

- The health care provider sends the Pap smear to a lab
- The clinic will let you know if the lab reports that the cells are not normal

If I have an abnormal Pap smear, will I get cancer?

- You will need follow up
- If not treated, it takes about 3 to 10 years for severe, abnormal changes to become cancer
- Mild changes often do not need treatment
- If not treated, some women will get better
- Regular Pap smears and treatment when needed can prevent most cancer of the cervix

What can I do to help avoid cancer of the cervix?

- Get regular Pap smears
- Do not smoke
- Eat healthy foods including dark green leafy vegetables and red/orange/yellow fruits and vegetables
- Do not have sex at a young age (before age 18)
- Abstain or do not have sex
- Limit your number of sex partners
- Talk with sexual partner about his past and current sexual partners
- Use a condom for all penis in the vagina sex
- Do not have sex with men with genital warts or other sexually transmitted diseases
- Do not have sex without a condom with men whose past partners have had cervical cancer

What if I have questions about my Pap smear?

- Talk with your health care provider at the family planning clinic
- Don't be afraid to ask any question you have

Pap Smear Record

Continue to record Pap smear examinations on the reverse side.

Source: Krames Health and Safety Education. Available for purchase at www.krames.com

Abnormal Pap Test Results



Understanding Your Diagnosis and Management Options

Pap Tests Can Put Time on Your Side

The Pap test is a way of finding cell changes in the **cervix**, the opening to your uterus. If your Pap test results were **abnormal**, you may be worried. The good news is that cervical problems, when caught early, can almost always be treated. This often can be done in your health care provider's office. This booklet will help explain your abnormal Pap test results and what to do next.

When Your Results Are Abnormal

Don't panic. An abnormal Pap test result can mean many things. You may simply have an infection. Or you may have a problem that could become cervical cancer. If so, know that this disease tends to progress slowly in its early stages. That's why yearly Pap tests are so important: A problem that is caught before it spreads beyond the cervix is more likely to be treated successfully.

Talk to Your Health Care Provider

Be sure to discuss your results with your health care provider. Find out about any follow-up tests you'll need. You may be asked to come back for a second Pap test in a few months. Or, you may be scheduled for an exam so your health care provider can get a closer look at your cervix. In either case, be sure to go to your follow-up visits. They are one of your best safeguards against future problems.



Your health care provider can answer your questions.

This booklet is not intended as a substitute for professional medical care. Only your doctor can diagnose and treat a medical problem.

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Why Cell Changes May Occur

The cervix is open to the vagina. Therefore, it is exposed to bacteria and viruses that can cause infection and damage delicate cervical tissue. Abnormal Pap test results are often linked to the *human papillomavirus* (HPV). This is a sexually transmitted virus that is the cause of genital warts (condyloma). HPV can also cause changes in cervical cells. Other things that can increase your chances for cervical cell changes are an infection, having sex at a young age, having many sexual partners, or smoking.

What You Can Do

If your Pap test results show an HPV infection, talk with your partner. Because HPV sometimes causes no symptoms for months or even years, your partner may be infected and not know it. Suggest that he see a health care provider, too. If you smoke, try to quit. Also, limit your number of sexual partners, and use condoms during sex. Finally, get regular Pap smears to catch changes early, before they can become a problem.

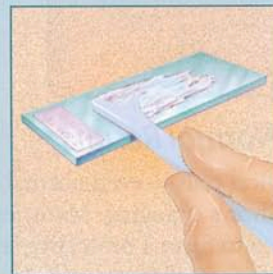


Discuss your Pap test results with your partner, especially if they show an HPV infection.

The Pap Test

The Pap test takes little time and may save your life. For several days before your test, don't douche or use vaginal creams. The test may include these steps:

- An instrument called a **speculum** gently holds the vagina open. This lets your health care provider see your cervix.
- A small brush or swab is used to take cells from several areas of the cervix. The cells are put into a liquid or on a slide. They are then sent to a lab where they are studied for changes. Your health care provider gets the results in a few days.



Cervical cells are put on a slide or into a fluid and sent to a lab for evaluation.

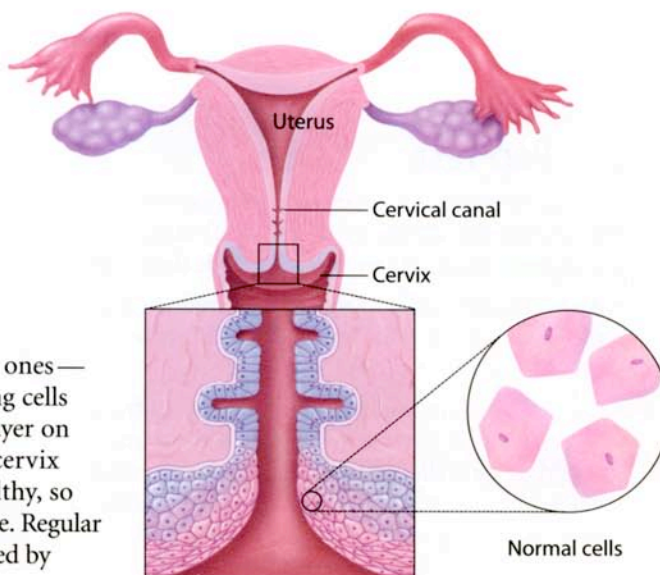
What Your Pap Test Shows

The lab studies your cell samples and reports any cell changes. Your health care provider can discuss these changes with you. In many cases, an abnormal Pap test is due to an infection. More serious cell changes range from abnormal cell growth (**dysplasia**) to cancer.

The Range of Pap Test Results

A **normal** result means the cells in your sample were normal. An **abnormal** result means some cells showed changes. Abnormal results are grouped by the type of cell changes. You may hear one or more of these terms:

- **Normal:** Only normal cells are seen.
- **Inflammation, reactive cellular changes:** Harmless changes are present.
- **ASCUS (atypical squamous cells of undetermined significance) or AGUS (atypical glandular cells of undetermined significance):** The results are unclear—cells may be abnormal.
- **Mild dysplasia, low-grade SIL (squamous intraepithelial lesion), CIN I:** Cells show certain distinct changes, possibly due to HPV.
- **Moderate to severe dysplasia, high-grade SIL, CIN II-III:** Cells show precancerous changes. Or, noninvasive cancer (**carcinoma in situ** or **CIS**) may be present.
- **Cancer:** Cancer has spread deep into or beyond the cervix.

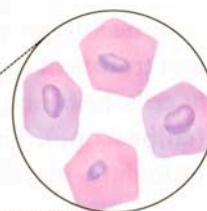
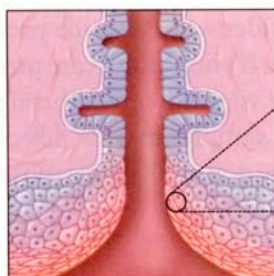


☐ Normal Results

Cervical cells—even normal ones—are always changing. Maturing cells flatten to form a protective layer on the surface of the cervix. A cervix with this type of cells is healthy, so the Pap test results are negative. Regular Pap tests are needed as specified by your health care professional.

☐ Inflammation

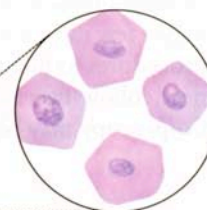
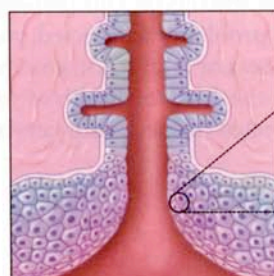
Inflammation may result from HPV, herpes, yeast, or other types of infection. Cell changes from inflammation are not normal, but are most often harmless. You may be given medication for an infection. A second Pap test may be needed in a few months to recheck your cervix.



Reactive cellular changes

☐ Mild Dysplasia

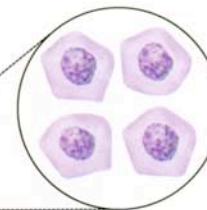
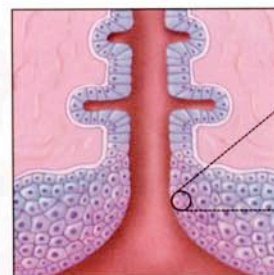
With dysplasia, some cells on the surface of the cervix are abnormal. Your health care provider may suggest more tests. You may have treatment to destroy or remove the problem cells before they can become cancerous.



Low-grade SIL, CIN I

☐ Moderate to Severe Dysplasia

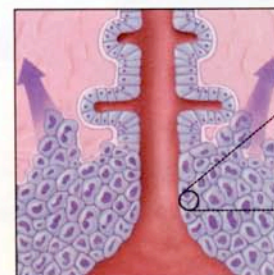
This means abnormal cells make up most of the cervical tissue. Further tests may be needed. Treatment is likely to be done to destroy or remove problem cells before they can become cancerous.



High-grade SIL, CIN II-III

☐ Cancer

Cancer occurs when abnormal cells spread from the surface into deeper parts of the cervix or beyond the cervix. Tests may be needed to assess the cancer's extent. This and other factors will determine the type of treatment you'll need.



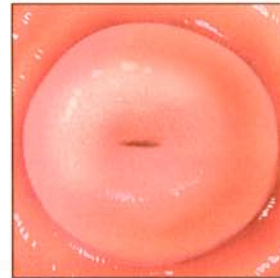
Cancer cells

Your Diagnosis and Treatment

Your health care provider will assess the problem and decide on the best treatment for you. If your health care provider needs a closer look at cells, he or she may view the cervix through a special instrument (**colposcope**). Tissue samples may be taken at this time. Other procedures may also be done to help diagnose or treat your problem.

Colposcopy

Your health care provider can use a colposcope to look at changes on the surface of the cervix. This painless test takes only a few minutes. If a problem is suspected, you may need procedures to further assess or treat it. Or, you may simply need follow-up visits to check on the health of your cervix. Colposcopy may be repeated to check your cervix over time.



Your health care provider can see the cervix more closely through a colposcope.



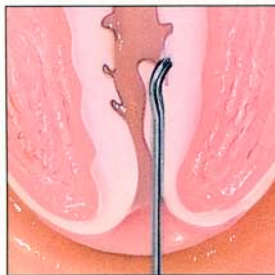
Other Procedures You May Need

Colposcopy may reveal that you need more tests or treatment. Most procedures can be done in the office and take no more than 15 to 30 minutes. The procedures are not painful. But you may have some cramping or light spotting for several days afterward. Ibuprofen or a non-aspirin pain reliever can help relieve any discomfort you feel.



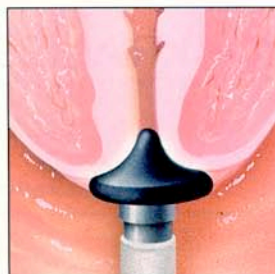
☐ Biopsy

Using the colposcope as a guide, your health care provider may perform a **biopsy**. A small sample of tissue is removed from the cervix and studied under a microscope for signs of cancer or other problems. More than one area of the cervix may be biopsied.



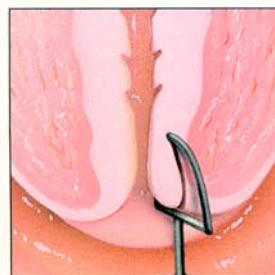
☐ Endocervical Curettage

The cervical canal cannot be seen with colposcopy. So, to detect problems in the cervical canal, you may need **endocervical curettage**. During this procedure, cells are scraped from the canal wall. These cells can then be studied under a microscope. This procedure is often done along with a biopsy.



☐ Destroying Abnormal Cells

Your health care provider may destroy abnormal cells on your cervix. This may be done by freezing the cells (**cryosurgery**). The cells may be destroyed with a beam of light (**laser surgery**). Or another method may be used.

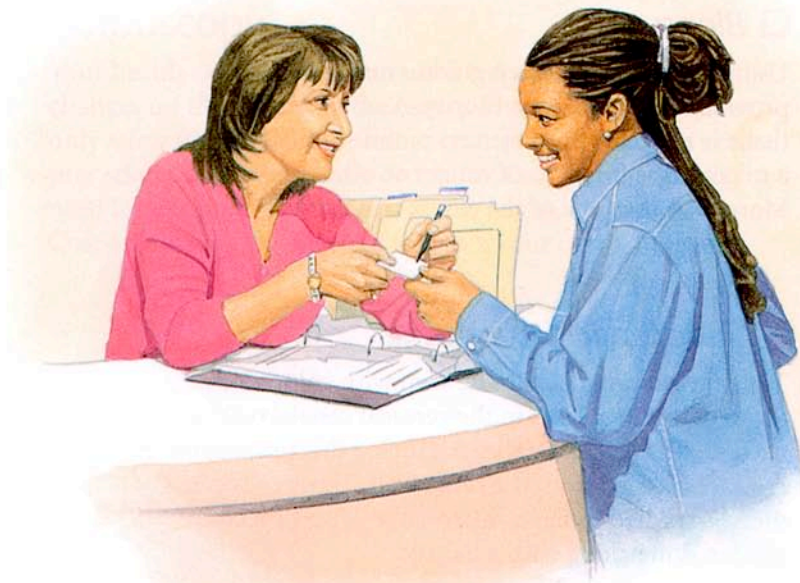


☐ Removing Abnormal Cells

To remove abnormal cells, your doctor may use a cutting laser, electric loop (Loop Electrosurgical Excision Procedure or **LEEP**), or another surgical instrument to remove a small section of the cervix. In some cases, a **cone biopsy** is done. This procedure removes a cone-shaped piece of tissue from the center of the cervix extending into the canal.

Follow Up for Life

To stay healthy, follow up with your health care provider. If you've had an abnormal Pap, your health care provider may want you to be checked more often. If treatment is done, the Pap test may be repeated in a few months. This helps make sure your cervix is back to normal. Give yourself the best chance for health: Have Pap tests as often as recommended for the rest of your life.



With contributions by:

Shelley Binkley, MD, FACOG
Carolyn V. Brown, MD, MPH
Scott Evan Eder, MD, FACOG
Susan Frank, RN
Frederick W. Hanson, MD, FACOG
Patrick W. Morell, MD

 **KRAMES**
Health and Safety Education

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Source: unknown

THE COLPOSCOPY

You are scheduled to have a special test during your next physical examination. This test is called a “colposcopy”.

WHAT IS A COLPOSCOPY??? A “colposcopy” (pronounced “coll-poss-co-pee”) is a procedure which is done by a specially trained doctor or nurse. It is done as a part of a pelvic exam, using a “colposcope”. While the doctor or nurse is doing the pelvic exam, he or she can look through the colposcope to see an enlarged picture of your vagina and cervix (the neck of your womb). This test does not hurt. It is like a regular pelvic exam, but it takes a little longer.

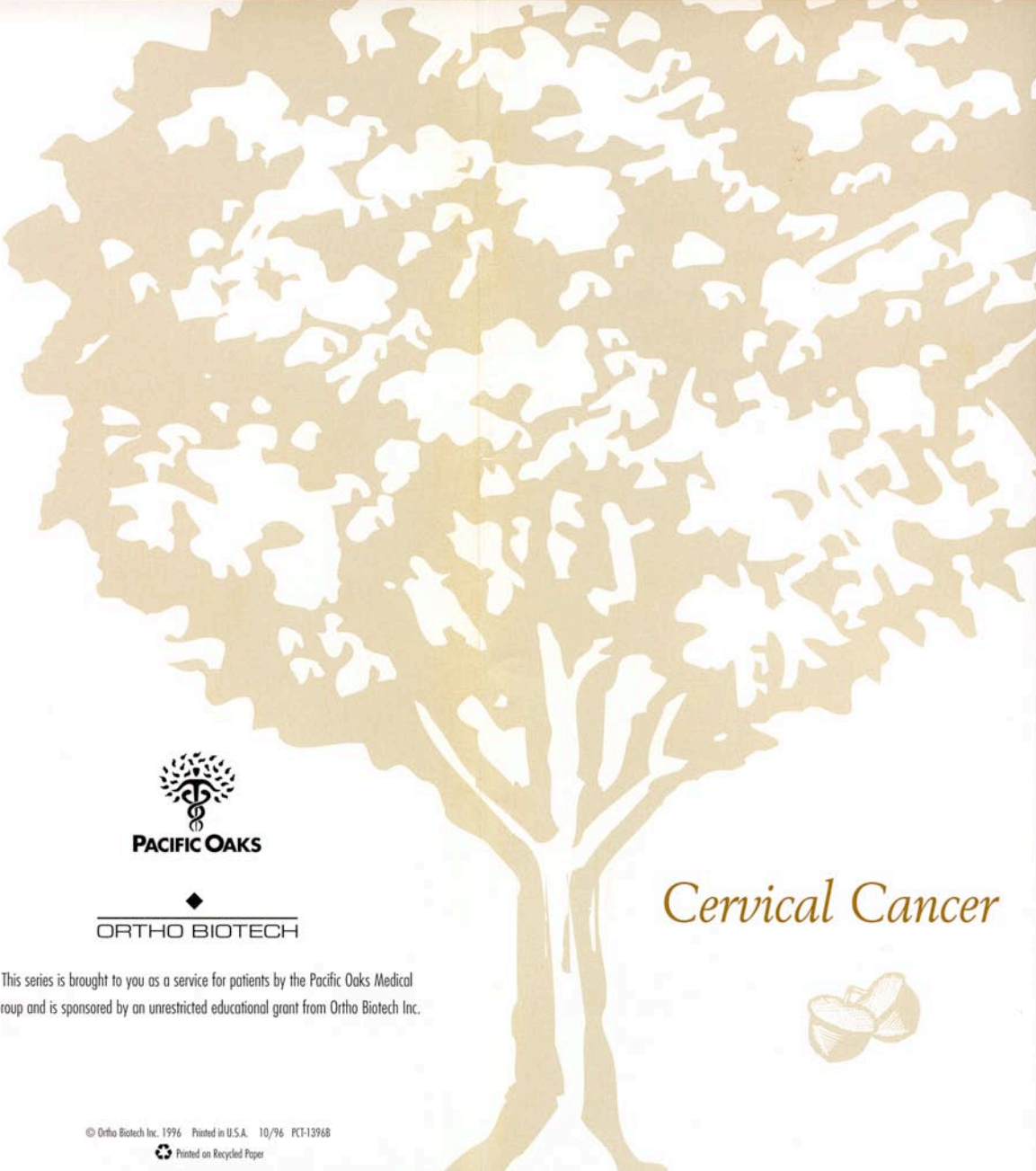


WHY DO I NEED A COLPOSCOPY? Colposcopy is usually ordered because your last Pap smear was not normal. This means that some cells from your cervix looked abnormal, and need to be checked out further. This does not necessarily mean that there is something wrong with you, it just means that another test should be done to understand why the cells looked abnormal.


DOES THIS MEAN THAT I HAVE CANCER? No it does not mean that you have cancer, but it is very important that the colposcopy be done so that if anything is wrong it can be treated right away. IF any abnormal cells are seen during the colposcopy, then a biopsy (removing a small piece of tissue) will be done. You might feel some cramps during the biopsy.

WHAT HAPPENS AFTER THE COLPOSCOPY TEST IS OVER? On your next visit to the clinic, the doctor or nurse will discuss all of the test results with you. They will help to plan what needs to be done next. **It is very important that you come to the next visit, and that you have a regular Pap smear every six months to one year from now on.**

Source: Pacific Oaks Medical Group. Contact by telephone at (310) 652-2562




HIV Patients Talk About . . .


PACIFIC OAKS

◆
ORTHO BIOTECH

This series is brought to you as a service for patients by the Pacific Oaks Medical Group and is sponsored by an unrestricted educational grant from Ortho Biotech Inc.

Cervical Cancer



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Overcoming System Barriers to Cervical Cancer Screening For HIV-Infected Women In A Clinical Setting, 2007

HIV Patients Talk About...



Non-Hodgkin's Lymphoma

Kaposi's Sarcoma

Cervical Cancer

Antiretroviral Therapy

Multiple Opportunistic Infections

Constitutional Symptoms



The *HIV Patients Talk About...* series has been prepared with the advice and counsel of patients and professionals at Pacific Oaks Medical Group in Los Angeles, California: Maria Castro, RN; Jodi Derr, RN; Brian Miller, patient; Ruth Pinter, RN; Chris Rice, RN; Robert Roe, patient; James Thommes, MD; Brad West, RN, and other friends.

HIV Patients Talk About...—A Series

Pacific Oaks, a leading medical group devoted to people who are HIV-positive, has put together a series of booklets for people who have been diagnosed with HIV infection. Patients volunteered to participate in discussions about what they believe patients with HIV infection need to know about living with HIV, HIV therapy, and diseases and disorders common to people with HIV infection. Information about each of these topics has been included in these booklets.

We hope these booklets help you feel better about managing your illness and more empowered to ask questions to get the answers you need to take charge of your health.

In this booklet, *HIV Patients Talk About Cervical Cancer*, women with HIV infection who have also been diagnosed with cervical cancer talk about aspects of coping with both illnesses.



PACIFIC OAKS



ORTHO BIOTECH

"I was more worried about cervical cancer than my HIV. HIV is a long-term thing. You can be careful and maybe ward off some of those infections. But I was very scared about the cancer. I figured it would advance real quickly, and that would be it. But I got treatment, and now I'm fine."


What Is Cervical Cancer?

The **cervix** is the lower portion of the uterus, or womb, that opens into the top of the vagina. It protects the inside of the uterus.

Occasionally, a few cells in the cervix begin to change and become abnormal. If these abnormal changes continue, the cells gradually become cancerous and spread. Untreated cervical cancer can be fatal. Fortunately, there are effective treatments for this disease.

What Is the Connection Between Cervical Cancer and HIV?

Any woman can get cervical cancer, but women who have human immunodeficiency virus (HIV) infection are at greater risk. In fact, cervical cancer can be one of the first signs of HIV infection in women.



"I found out I had cancer and HIV at the same time. I completely freaked out! I'm a recovering addict, and for about a month, I went right back on drugs. I'm OK now, but it was a shock."

Some women mistakenly think of cancer as a death sentence. Finding out that they have cervical cancer can be even more frightening than learning they have HIV infection. Fortunately, there are effective treatments for this type of cancer.

How Would I Know If I Have Cervical Cancer?

A very simple test called a **PAP smear** is used to examine the cells in the uterus. The test is painless and takes only a few minutes.

The PAP test has saved many lives. Since there are no warning symptoms of early cervical cancer, a woman is not likely to suspect she has the disease until she is very sick. Common symptoms of invasive disease include watery, blood-tinged vaginal discharge, most commonly seen after sexual intercourse. The PAP test can help doctors diagnose cervical cancer at an early stage and treat patients earlier.



How Does a Woman Get Cervical Cancer?

In some cases, infection with a virus called **HPV (human papilloma virus)** can lead to cervical cancer. Since this virus is passed through sexual intercourse, the more sexual partners a woman has, the greater her risk of becoming infected with HPV. However, not all women with cervical cancer have HPV, and not all women with HPV develop cervical cancer.

Other causes of cervical cancer are not clear at present. However, vaginal douching (or not douching) is not believed to be a factor, and the tendency to get cervical cancer is not inherited.

What Is Treatment Like?

Treatment for cervical cancer depends on how advanced the disease is. Precancerous or early-stage cancerous cells can be removed by **biopsy** or by various treatments—electricity, freezing, laser, or surgery. Advanced cervical cancer calls for a **hysterectomy, chemotherapy, or radiotherapy** to get rid of the diseased tissue.



"At first, I just panicked because I have this brand new little baby. I thought, 'What will happen to him if I die now?' But my doctor explained the procedures, and I came out of everything OK."



Can I Still Have Sexual Relations After Treatment? What About Having Children?

Treatment for early-stage disease does not usually affect a woman's ability to have children. However, women who have a hysterectomy will not be able to become pregnant. Other treatments for advanced cervical cancer, such as chemotherapy and radiation implants, also prevent having children. Regardless, a woman who is HIV-positive should be aware that she could potentially transmit the virus to her unborn child.

Sexual activity is another matter. Sexual desirability is mainly a state of mind. If *you* think you are desirable, others will too—regardless of what treatment you've had. And none of the treatments for cervical cancer will reduce your ability to have sexual relations. But, as a woman with HIV infection, you could potentially infect your sexual partners if you don't practice safe sex.



"My energy level? There isn't one. Most days I don't feel like doing anything."

Why Am I So Tired All the Time?

If you are always tired, it may be because you have **anemia**. People with anemia do not have enough mature red blood cells. Red blood cells contain **hemoglobin**, which carries oxygen to the tissues of the body. Low levels of oxygen result in fatigue and little energy.

Approximately 80% of people with HIV have some degree of anemia. Many factors can cause anemia in HIV-infected people. HIV infection itself can cause anemia. In addition, **antiretrovirals**, chemotherapy, and many other drugs used to treat people with HIV infection can reduce the number of red blood cells in the body.

"My kids don't want to hear 'I don't feel good. I'm tired.' They say, 'Still?! You were tired yesterday. How can you be tired today, too?'"

Severe anemia can be life-threatening. But even mild to moderate anemia can rob a person of energy and make it hard to enjoy life. Anemia

and fatigue are especially difficult for women who have small children to take care of.

Can Anything Be Done About Anemia?

There are two ways to treat anemia. Severe anemia is usually treated with blood transfusion. Since transfusion always carries the risk of infection or reactions, patients generally are not transfused unless their anemia is serious.

Another way of treating anemia is with a drug called PROCRIT® (Epoetin alfa), which is the same as the hormone **erythropoietin** (e-rith-ro-poy-e-tin), naturally produced in your body to stimulate red blood cell production. PROCRIT injections stimulate the body to produce more red blood cells. PROCRIT doesn't carry the risks of infection and reactions that transfusion does, and it can be used to treat mild to moderate as well as more serious anemia. Any side effects that occur while taking PROCRIT are believed to be from the HIV, not PROCRIT.



"My doctor is great, but a lot of them gloss over the issue of fatigue. They say, 'Oh, that's just part of having HIV.' But that isn't good enough! I was tired all the time, but I have a 3-year old who wasn't. I have a 3-year-old who would play with the stove if I fell asleep. I had to do something about my anemia, so I went on PROCRIT."



You can also make some changes in your diet and daily habits to deal with anemia. Your nurse can give you tips on diet, conserving energy, and other ways to help you feel better.

What Can HIV-Positive Women Do to Protect Against Cervical Cancer?

- **Be sure to have a PAP test regularly.** If you are HIV-positive, you should have a PAP test every 6 months so that your doctor can tell if you have any abnormal or cancerous cells and make plans to remove them.

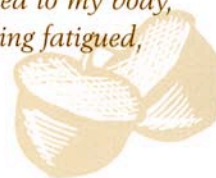
"I always have my PAP smears. It's important to keep up your appointments and have them done. And if you come across anything that's abnormal, take care of it—don't just let it go."

- **Talk to your doctor.** Women with HIV infection have a higher risk of cervical cancer. Knowing that you are HIV-positive will alert your doctor to watch you more closely for signs of cervical cancer.

"If I had known about the connection between HIV and cancer, it would have made a huge difference! I wouldn't have slipped and let my PAP smears go."

- **Stay on top of your own health.** If the people at your clinic forget to schedule your PAP test, remind them. If you don't understand something, ask questions. Most important, if your doctor doesn't take your concerns seriously, find one who does.

"We need to ask questions. If we don't ask the questions, we won't get the answers. Also, listen to your body—that's very important! I should have listened to my body, because I was feeling fatigued, really tired."





Source: U.S. Department of Health and Human Services, National Institutes of Health, National Cancer Institute. Available at www.cancer.gov

Pap Tests

A HEALTHY HABIT FOR YOU



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
National Institutes of Health • National Cancer Institute

Call your family doctor or local medical clinic **TODAY** for a Pap test appointment.

My appointment for a Pap test

Date _____

Time _____

Place _____

Telephone _____

FOR MORE INFORMATION ON THE PAP TEST

Visit the National Cancer Institute's Web site at www.cancer.gov or call the National Cancer Institute's Cancer Information Service at 1-800-4-CANCER (1-800-422-6237). TTY: 1-800-332-8615.





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(RL-3)



1. What is a Pap test?

The Pap test is used to find cell changes in the cervix. It can find problems that can be treated before they turn into cervical cancer. A Pap test also can find cancer early. If cervical cancer is found early, it's easier to cure.

2. How is a Pap test done?

A Pap test is done during a pelvic exam. You will lie on an exam table with a sheet over your legs and stomach. Next, you'll put your feet on the holders called stirrups and let your knees fall to the side. A nurse or doctor uses a plastic or metal instrument called a speculum to look inside your vagina. He or she then uses a small, soft brush to take a few cells from your cervix (opening to the womb). This test takes only a few seconds. A lab will check these cells for cancer or other problems. Your doctor may also do an HPV test at this time.

3. What is an HPV test? Do I need one?

Almost all cervical cancers are caused by viruses called HPVs (Human Papillomaviruses). If your Pap test results are unclear, your doctor may want to perform an HPV test. Having an HPV test is like having a pap test. If you are over age 30, talk with your doctor to learn if an HPV test is right for you.

4. What else happens during a pelvic exam?

The nurse or doctor will look at your vaginal area to see if you have any signs of infection or other problems. After the Pap test, the nurse or doctor will check your tubes, ovaries, and uterus (womb) by putting two gloved fingers inside your vagina. With her other hand, she will feel from the outside for any lumps or tenderness. This takes only a few minutes. Once the exam is over, you can get dressed.

5. Could I have cervical cancer and not know it?

YES—often cervical cancer causes no symptoms or pain.

6. Where do I get a Pap test?

- Doctor's office
- Medical clinic
- Local health department
- Student health services

7. If I've gone through menopause, do I still need a Pap test?

Most women still need to get Pap tests. This decision depends on your age and past Pap test results. Talk with your doctor about what is right for you.

8. If I've had a hysterectomy, do I still need a Pap test?

After a hysterectomy, you still need to get a Pap test if:

- You had a partial hysterectomy (an operation that removed the uterus but not the cervix)
- You had a total hysterectomy (an operation that removed the uterus and the cervix) to treat cervical cancer or a condition that might lead to cancer

You may not need to get Pap tests if you have had a total hysterectomy for other reasons (e.g., fibroids). Talk with your doctor about what is right for you.

9. When can I stop getting Pap tests?

If you are age 65 or older, talk with your doctor about whether you still need to get Pap tests. You and your doctor can decide what testing schedule is right for you based on your past Pap test results.

10. A Pap test is important to me because it can:

- Find abnormal cervical cell changes before they have a chance to become cancerous.
- Tell if you have cancer of the cervix early—while it's still easier to cure.

APPENDIX C: SAMPLE TRACKING AND PATIENT INFORMATION FORMS

Source: New York State Department of Health AIDS Institute. (2000). *Promoting GYN CARE for HIV-Infected Women: Best Practices from New York State*. Available for download at <http://www.ihl.org>

SAMPLE GYN PROGRESS NOTE PAGE	
GYNECOLOGY	
A. History	
G_____	P_____
LMP: _____	
Menses: _____	
STD History: _____	

Last PAP: _____ Results: _____	
Last Mammogram: _____	
Surgical History: _____	
Sexual Activity: _____	
Contraception/Protection: _____	

B. Pelvic Exam	
Breasts: _____	
Pelvic: _____	
Wet mount/KOH: _____	

C. Assessment/Plan _____	

Follow-up Appointment: _____	

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Source: New York State Department of Health AIDS Institute. (2000). *Promoting GYN CARE for HIV-Infected Women: Best Practices from New York State*. Available for download at <http://www.ihl.org>

SAMPLE GYN STICKER

GYN HISTORY

Present Symptoms: None _____ Yes: _____

Past Infections: None _____ GC _____ Chlamydia _____ Syphilis _____ PID _____ Other: _____

Previous PAP smears: Normal _____ Abnormal: _____

L.M.P. _____

Sexually active: No ___ Yes ___ HIV Education Given: Yes ___ Referred: _____

PAP/STD Education Given: Yes ___ Referred: _____ GYN Referral: No ___ Yes ___

Partner Notification: New Partner(s): _____

Source: New York State Department of Health AIDS Institute. (2000). *Promoting GYN CARE for HIV-Infected Women: Best Practices from New York State*. Available for download at <http://www.ihl.org>

SAMPLE CLINICAL MANAGEMENT PATIENT INFORMATION SHEET

PPD	Date / / neg (no induration) positive (mm)___	Date / / neg (no induration) positive (mm)___	Date / / neg (no induration) positive (mm)___	Date / / neg (no induration) positive (mm)___
Pelvic Exam				
PAP smear	Date / / normal abnormal	Date / / normal abnormal	Date / / normal abnormal	Date / / normal abnormal
GC culture	Date / / negative positive	Date / / negative positive	Date / / negative positive	Date / / negative positive
Chlamydia	Date / / negative positive	Date / / negative positive	Date / / negative positive	Date / / negative positive
VDRL	Date / / negative positive (titer) ___	Date / / negative positive (titer) ___	Date / / negative positive (titer) ___	Date / / negative positive (titer) ___
FTA	Date / / negative positive	Date / / negative positive	Date / / negative positive	Date / / negative positive
Toxoplasma Serology	Date / / negative positive	Date / / negative positive	Date / / negative positive	Date / / negative positive
HBs Antigen	Date / / negative positive	Date / / negative positive	Date / / negative positive	Date / / negative positive
HBs Ab	Date / / negative positive	Date / / negative positive	Date / / negative positive	Date / / negative positive
HB core Ab	Date / / negative positive	Date / / negative positive	Date / / negative positive	Date / / negative positive
Hep C Ab	Date / / negative positive	Date / / negative positive	Date / / negative positive	Date / / negative positive

	Date	Date	Date	Date
Annual Exam	/ /	/ /	/ /	/ /
Dental Exam	/ /	/ /	/ /	/ /
Eye Exam	/ /	/ /	/ /	/ /
Pneumovax	/ /			
Influenza Vaccine	/ /	/ /	/ /	/ /
Heb B Vaccine	/ /	/ /	/ /	
HBs Antigen	/ /			
HBs Abs	/ /			
HB Core Ab	/ /			
Hep C Ab	/ /	/ /	/ /	


Viral Load	Date	Date	Date	Date	Date	Date

Viral Load (continued)	Date	Date	Date	Date	Date	Date

CD4	Date	Date	Date	Date	Date	Date

CD4 (continued)	Date	Date	Date	Date	Date	Date

Source: Christiana Care Health System. Visit www.christianacare.org



CHRISTIANA CARE
HEALTH SERVICES

Place name label here

INITIAL NURSE INTERVIEW

DEMOGRAPHICS: must check one in each column

Sex <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Transgender	Marital Status <input type="checkbox"/> Single <input type="checkbox"/> Married <input type="checkbox"/> Divorced <input type="checkbox"/> Widowed	Race <input type="checkbox"/> American Indian <input type="checkbox"/> White <input type="checkbox"/> Asian <input type="checkbox"/> Black <input type="checkbox"/> Multiple Race <input type="checkbox"/> Native Hawaiian/ Other Pacific Islander <input type="checkbox"/> Not Specified	Ethnicity <input type="checkbox"/> Hispanic or Latino/a <input type="checkbox"/> Non-hispanic or Non-Latino/a	Source of Referral <input type="checkbox"/> DPH <input type="checkbox"/> Self <input type="checkbox"/> Case Manager
--	---	--	--	---

Place of birth: _____

HIV EXPOSURE

Date of HIV testing	Risk Behavior
Date of previous HIV testing (and results) Partner notification: <input type="checkbox"/> Patient declines <input type="checkbox"/> Patient agrees to Public Health referral <input type="checkbox"/> Patient chooses to notify partners	Sex with male <input type="checkbox"/> Yes <input type="checkbox"/> No
	Sex with female <input type="checkbox"/> Yes <input type="checkbox"/> No
	Injecting drug user <input type="checkbox"/> Yes <input type="checkbox"/> No
	Received clotting factor for hemophilia/coagulation disorder (if yes, circle all that apply) <input type="checkbox"/> Yes <input type="checkbox"/> No <small>Factor VIII Factor IX Other</small>
	Received transfusion of blood/blood products (if yes, give dates) <input type="checkbox"/> Yes <input type="checkbox"/> No
	Received transplant of tissue/organs or artificial insemination <input type="checkbox"/> Yes <input type="checkbox"/> No
	Worked in health care or clinical lab <input type="checkbox"/> Yes <input type="checkbox"/> No
	Heterosexual relations with:
	∞ Injecting drug user <input type="checkbox"/> Yes <input type="checkbox"/> No
	∞ Bisexual male <input type="checkbox"/> Yes <input type="checkbox"/> No
∞ Person with hemophilia/coag disorder <input type="checkbox"/> Yes <input type="checkbox"/> No	
∞ Transfusion recipient with HIV <input type="checkbox"/> Yes <input type="checkbox"/> No	
∞ Transplant recipient with HIV <input type="checkbox"/> Yes <input type="checkbox"/> No	
∞ Person with AIDS/HIV, risk not specified <input type="checkbox"/> Yes <input type="checkbox"/> No	

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Place name label here

ALLERGIES
CURRENT MEDICATIONS
VACCINATION HISTORY
PPD Hepatitis B Pneumovax Influenza Td
SUBSTANCE USE HISTORY
Alcohol Tobacco Illicit drugs
PREFERRED LANGUAGE
HIGHEST EDUCATION LEVEL COMPLETED
HOUSING/LIVING ARRANGEMENTS: <input type="checkbox"/> Permanent Housing (includes apartments, houses, foster homes—not time limited) <input type="checkbox"/> Non-Permanent Housing (includes homeless, transient or transitional housing, shelters, vehicles or street) <input type="checkbox"/> Institution (includes residential (group homes & extended treatment), healthcare & correctional facilities) <input type="checkbox"/> Other (anything not listed above)

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Place name label here

TEACHING/COUNSELING

- | | |
|---|--|
| <input type="checkbox"/> Care Coordinator Booklet | <input type="checkbox"/> HIV Terms/Definitions |
| <input type="checkbox"/> Nutrition Instruction | <input type="checkbox"/> Risk Reduction |
| <input type="checkbox"/> Resource Guide | <input type="checkbox"/> Medication/Adherence |

NURSING NOTES/COMMENTS

Vital Signs:	BP	Pulse	Resp.	Temp
--------------	----	-------	-------	------

Pain Assessment: Are you experiencing pain?	Yes	No	If yes: list location & intensity

DISCHARGE PLAN

Baseline Work-Up

Labs: CBC, CMP, U/A, CD4, HIV RNA Quant, RPR, ToxoIgG, HbsAg, anti-Hbc, or anti-Hbs, anti-HCV, cardiac risk evaluation (lipid profile), Anti-HAV total

CXR

PPD

Return Visit Date:

SIGNATURE

DATE _____



Place name label here

INITIAL MD/NP ASSESSMENT

DATE _____

HISTORY OF PRESENT ILLNESS

Date:	
CD4	Viral Load

PAST MEDICAL HISTORY

MEDICAL HISTORY
History of Anti-retrovirals
Opportunistic Infections
Tuberculosis or exposure
Hepatitis
Sexually Transmitted Disease
Mental Health

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MEDICAL HISTORY (CONTINUED)

SURGICAL HISTORY

OB/GYN HISTORY

If currently pregnant: What trimester : _____

FAMILY HISTORY

REVIEW OF SYSTEMS

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Place name label here

PHYSICAL EXAM	DATE
---------------	------

Height	Weight	BP	Pulse	Temp	Resp
--------	--------	----	-------	------	------

	*Neg.	Not Done	Abnormal	Comments
1. General	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
2. Head	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
3. Eyes/Fundosopic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
4. ENT	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
5. Dentition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
6. Neck and thyroid	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
7. Breast exam	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
8. Chest and lungs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
9. Cardiac	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
10. Abdomen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
11. Pelvic exam (female)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
12. Genitals (male)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
13. Rectum and anus	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
14. Musculo-skeletal	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
15. Peripheral Pulses	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
16. Neurologic (DTR's):	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
17. Neurologic (CNII-XII):	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
18. Neurologic): (motor sensory cerebellar gait)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
19. Mental Status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
20. Lymph Node Stations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
21. Skin	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

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Place name label here

ASSESSMENT

1. (circle one) HIV+ AIDS defined _____ Diagnosis pending work-up

2.

3.

4.

PLAN

Baseline Work-Up (if not yet done)
 Labs: CBC, CMP, U/A, CD4, HIV RNA Quant, RPR, ToxoIgG, HbsAg, anti-Hbc or anti-Hbs,
 anti-HCV, cardiac risk evaluation (lipid profile), Anti-HAV total

CXR

PPD

Referrals (circle) OB/GYN, Ophtho, Dental, Nutrition, Mental Health, Social Work

TREATMENT

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Initial History and Physical Assessment Form

*Christiana Care Health Services
Wilmington, Delaware, USA*

For all new patients in the HIV program, the nurse will complete the first three pages of this form during the patient's initial visit to the clinic. The doctor/nurse practitioner who performed the patient's physical assessment will then finalize the form.

The initial nurse interview session and doctor/nurse practitioner visit include the following:

- Counsel and educate regarding HIV disease process
- Explain the HIV program structure
- Complete the Initial History and Physical Assessment Form

Background

This form was developed several years ago as a comprehensive and consistent nursing assessment tool and as a way to insure that information needed for the CARE Act yearly reports was collected in a standard fashion.

Both nursing and medical staff contributed to the development of this form. This form is currently used by all sites of the Christiana Care Health System HIV Program and is adapted as necessary to reflect current guidelines in HIV care.

Directions

During the patient's initial visit to the clinic, the nurse completes the "Initial Nurse Interview" section on the first three pages of the form. At this point, the patient is sent for baseline labs and x-ray and scheduled for an initial doctor/nurse practitioner visit. When the patient returns for their scheduled visit, the doctor/nurse practitioner who performs the initial examination completes the form.